

Connected Health Cities

End of Project Report

Clinical Pathway: Alcohol-related liver disease



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ABSTRACT:

The model for a Learning Healthcare System for the North West Coast pilots was to first establish a Trusted Research Environment (TRE) hosting anonymised hospital administrative data.

Work on the alcohol-related liver disease (ARLD) pathway involved iterative, multistakeholder development of new methods to identify cohorts of cases of ARLD from administrative datasets, characterise case mix and undertake granular segmentation and riskadjustment, creating new approaches to monitoring mortality and post-discharge outcomes, comparing provider performance and of feeding data back to the front line.

The information tools were shared with the local health economy and integrated into an existing quality improvement (QI) programme – adding value to local efforts to improve care processes and establishing new evidence for successful reductions in avoidable mortality for ARLD in the region.

The methods and benchmarking tools have gained traction with local, national and international teams, creating opportunities to disseminate the work more widely.



INTRODUCTION:

The model for a Learning Healthcare System for the North West Coast pilots was to first establish a TRE hosting anonymised hospital administrative data for the whole region.

This data was made securely and remotely accessible to a team of university-based data scientists working closely with front line NHS teams.

Each of three pathways (alcohol-related liver disease, Chronic Obstructive Airways Disease (COPD) and epilepsy) shared a common core aim - to develop methods to leverage greater insight from currently available datasets and to share this information with the healthcare system to support care QI.

Crucially, the projects were developed iteratively with direct engagement of those delivering care "bottom-up" and involved key players in local, regional and national data-driven QI initiatives.

The methodologies and results were shared with the local health economy, seeking to bring new data-driven approaches to enabling, monitoring and guiding local QI initiatives.

The work focused on providing new analytical tools to enhance the health care system's ability to accurately track emergency care pathways, identify variation in activity, process and outcome and opportunities to improve care.

Having established novel analytical approaches to the use of administrative data, opportunities to enhance the analytical tools through linkage to other datasets were explored, including primary care, and by exploring alternatives to traditional statistical approaches.

ALCOHOL-RELATED LIVER DISEASE

Alcohol harm rates in England are persistently high and place a major burden on acute services.

In 2016–17, there were 1·1 million hospital admissions for which an alcohol-related condition was coded on discharge.

Liver disease is the leading cause of deaths from an alcohol-specific condition.

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ARLD typically presents late and often with fatal complications. Although a focus on prevention and early detection is vital, there remains the challenge of optimising care for those presenting as emergencies with this complex and life-threatening condition.

In the UK it is estimated that up to 75% of fatal liver cirrhosis is undetected before a patient's first hospitalisation.

This suggests that, for many patients, their earliest contact with liver and alcohol services occurs following an acute crisis and emergency admission.

The North West region of England has one of the country's highest rates of alcohol-specific deaths and ARLD is the dominant cause.

Early inpatient intervention with evidence-based treatments has the potential to save lives. In 2013, a UK report '*Measuring the Units, National Confidential Enquiry into Patient Outcome and Death*' (NCEPOD) described suboptimal care for patients dying during hospitalisation for ARLD.

Less than half of cases were judged to have received 'good care' in hospital and potentially avoidable deaths were identified.

A year later, the *Lancet Commission* highlighted wide variation in inpatient mortality, describing a "*postcode lottery of liver services*" and a parliamentary group raised "grave concerns" about patchy provision of high-quality specialist care.

Since the NCEPOD report, there have been various local and national initiatives to improve care quality and reduce variation.

Although evidence of improvements in care processes have been reported by some UK hospitals through local audit, no evidence has emerged of improved patient outcomes (i.e. reduced mortality).

Despite an abundance of 'alcohol statistics', several reports had highlighted a lack of reliable data or methodologies to accurately monitor true levels of emergency activity, care processes and outcomes for ARLD.

Current metrics of hospital activity and mortality continue to rely on the use of hospital episode statistics (discharge coding). A *Lancet Commission* report noted that metrics of casemix adjusted mortality derived by DrFoster and NHS Digital National Statistics both demonstrated high levels of variation between English hospitals, but identified different hospitals as having potentially "outlying performance."



Such metrics combine all admissions and readmissions, regardless of disease history or duration, and apply only simple case-mix adjusters (eg. age, co-morbidity).

Hence, routine statistics do not track individual patient pathways from a standardised starting point, nor consider different clinical presentations of ARLD with condition-specific complications and varying treatment pathways (eg. bleeding, acute kidney injury, ascites).

This suggested the need to develop better ways to interrogate the datasets, to identify cohorts of ARLD-related admissions, extract information on case mix and complications, and track individual patient pathways from a standardised starting point.

A key aim of this project was to work with clinical experts to leverage greater insight from existing datasets and provide new tools to support the monitoring of existing quality improvement initiatives and to help identify opportunities for intervention.

We sought to embed the work into established regional data-driven quality improvement activities for ARLD to identify gaps in capability and thereby focus on creating analytical tools that added value to existing local learning healthcare system.



METHODS:

OVERVIEW OF MAIN AREAS OF WORK

Working with front line teams, the CHC team at the University of Liverpool produced a series of analytical methods and tools to identify cohorts of ARLD patients from within the anonymised data held within the TRE.

These tools describe sociodemographic and clinical characteristics (case-mix), track journeys through the hospital system (admissions, A&E attendances and clinic appointments) and create metrics of the care process and outcome.

Statistical models were generated to allow risk-adjustment to enable benchmarking between providers and across time.

Data visualisations and maps were created to populate reports and a prototype 'dashboard' targeting hospital teams and other stakeholders. A series of 'use cases' were identified to deploy the information tools to enhance and support QI activities for ARLD pathways.

Key areas of methodological development were:

- Development and validation of diagnostic coding algorithms
- Pathway mapping, creating of novel composite metrics and 'chronotypes'
- Risk-adjustment models using greater granularity of case-mix than traditional approaches
- Geographical mapping of hot spots for local activity and outcomes
- Hospital-level reports and prototype "dashboard" development
- Deployment into a 'live' data system to generate a prediction model for readmissions using machine learning methodology (in collaboration with the Innovation Agency, Liverpool Clinical Commissioning Group and The Hartree Centre)
- Application to linked national datasets (CPRD) to explore primary care data linkage



SPECIFIC USE CASES FOR DEPLOYING THE ANALYTICAL TOOLS

The informatics tools developed by the team were deployed in a number of 'use cases', including:

Use Case 1 – Collaboration with regional quality improvement programme for ARLD (Advancing Quality Alliance) with provision of new insights into pathway outcomes and a formal evaluation of impact of the QI programme on mortality using independent CHC data.

Use Case 2 – Provision of standardised data reports for ARLD pathways containing novel metrics for local clinical teams to improve awareness of variation in outcomes and identify local opportunities for pathway improvement.

Use Case 3 – Provision of bespoke reports to local stakeholders on-demand, including support for a local hospital with internal mortality review for ARLD.

Use Case 4 – Deployment of algorithms to support development of a prediction model within a 'live' business intelligence system, focusing on predicting readmission of ARLD cases and using machine learning techniques (in collaboration with Innovation Agency, Liverpool CCG and The Hartree Centre).

Use Case 5 – Evaluating the role of primary care contacts in the ARLD care pathway through analysis of national linked hospital and general practice data (CPRD).



RESULTS:

OVERVIEW OF THE DEVELOPMENT OF INFORMATION TOOLS

In the first phase of the work, the team developed and tested new approaches to the interrogation of the datasets.

It confirmed that traditional simplistic methods for identifying patients with ARLD from diagnostic codes were insufficiently sensitive to capture all the relevant cases and admissions – reflecting the complexity and variability of the emergency presentations of the condition.

Working with clinical experts, the team established new code libraries and algorithms to more accurately capture true workload – showing that up to 49% of admissions for ARLD are 'missing' from traditional statistics.

A **cohort discovery (diagnostic) algorithm** comprising four main coding patterns, over 80 eligible primary diagnoses and more than 2,500 unique ICD-10 code sequences was developed.

Compared to a simple 'traditional' algorithm (six specific codes for ARLD in primary position, as used in routine statistics), the algorithm had superior sensitivity for detecting true cases of ARLD (87.5% v 62.5%) when compared with the gold standard review of clinical records whilst retaining high specificity (93% v 100%).

The implications for under-estimating true bed occupancy and demand for 'liver beds' amounted to 20 per day across seven Cheshire and Merseyside hospitals included in the analysis.





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The team created linkages between three NHS datasets (admitted patient care, accident and emergency attendance and outpatient visits), and established a **common starting point for tracking care pathways** – focusing on the first (or 'index') emergency admission for each patient, the outcome (including death) and the post-discharge journey for those discharged alive.

Composite metrics of 90-day post-discharge outcome were developed, moving beyond simple measures (eg. '30-day readmission rates') to metrics that combined key events from the three datasets.

Hence, different 'types' or patterns of the patient journey were defined according to the occurrence of unfavourable (eg. A&E attendance or readmission; failure to attend clinic) and favourable events (eg. day-case treatments, and avoidance of unplanned care). These journey metrics were named '**chronotypes**'.



Statistical models were constructed to establish case-mix factors associated with key outcomes (e.g mortality, readmission, 'successful' pathways), populating the datasets with novel flags to allow greater segmentation of cases according to specific disease complications.

This allowed more advanced case-mix adjustment than traditional NHS statistics, establishing a more 'level playing field' for **studying variations between hospitals and areas** and allowing the study of **time trends**.

Compared to the standard approach to risk adjustment based on a limited set of generic casemix variables, the final model for generating a standardised hospital mortality rate for index admissions for ARLD was found to explain a six-fold greater prediction of expected deaths



(pseudo-R-squared 30% versus 5%) – thereby increasing opportunities to detect genuine unwarranted variation in outcome and reducing the risk of identifying spurious outliers.

MAPPING

Mapping capabilities were developed to create heat maps of metrics for a variety of geographical levels of detail.

This included standard geospatial statistical units (Lower and Middle Layer Super Output Areas), traditional boundaries based on aggregation of GP practices into CCG footprints, and also some bespoke units such as 'GP neighbourhoods' (based on listings of practices obtained from local stakeholders) and a range of alternative approaches to mapping emergency catchment populations for each acute Trust.

The latter included assigning each Lower Layer Super Output Area to one hospital-based on where the majority (>50%) of emergency admissions were admitted, including 'all-cause' catchment areas and condition-specific catchment areas.

Small area maps were used to plot crude and age/sex standardised rates of admissions, and also to create novel visualisations of patient pathway outcomes (eg. the proportion of cases from each area with a positive pathway outcome at 90 days, based on the composite metrics or 'chronotypes'). Location of hospitals and GP practices were also generated.



Mapping to define emergency catchments' for individual hospitals

Mapping to show emergency case load (crude counts of admissions) according to geographical areas using the ARLD algorithm





Focus on an admission 'hotspot', with visualisation of proportion of cases with different 90-day pathways outcomes (chronotypes)



RESULTS FROM THE SPECIFIC USE CASES

Use Case 1 – Collaboration with regional quality improvement programme for ARLD (Advancing Quality Alliance) with formal evaluation of impact on mortality using independent CHC data and risk-adjusted metrics of care outcomes

Working closely with the Advancing Quality Alliance (AQ), the Data Lab applied its analytical approaches to undertake a formal evaluation of the regional quality improvement programme which had launched in 2015 (The AQ Alcohol-related Liver Disease Collaborative).

The AQ programme was focused on driving improvements in acute care of liver disease through the implementation of a 'bundle' of process measures at participating hospitals.

Although the programme was seeking to demonstrate improvements in care processes through local audits, the project lacked the methods to monitor trends in risk-adjusted mortality – a challenging task given the complexity of case mix and patient journeys.

The Data Lab deployed its rules and algorithms for cohort identification and its new approach to extracting flags for case-mix to examine whether there were signals in the administrative hospital data held in the TRE to suggest unexplained variation in risk-adjusted mortality between hospitals prior to the AQ intervention (to identify 'outliers').

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Statistical modelling was then applied to explore time trends, determining whether the local QI programme was associated with a reduction in unexplained variation between hospitals (elimination of 'outliers') and a reduced risk of inpatient mortality over time.

Analysing data on 3,887 index admissions for ARLD across seven hospitals, the team showed that three hospitals had a higher than expected mortality in the year prior to the AQ intervention (ie. statistical 'outliers' based on our experimental case mix-adjusted mortality measure).

This suggested the possibility of 'avoidable' deaths and hence opportunities for reducing inpatient mortality. Analysis of local audit data provided by AQuA allowed the team to show that, as a group, the three hospitals also had lower scores on several of the AQ process measures compared to the non-outlier group before the QI programme.

Tracking trends over time following the AQ intervention demonstrated a step-wise reduction in the variability in risk-adjusted mortality between hospitals and was able to show that by the end of the observation period there were no outliers.

This provided independent evidence to suggest that the local AQ programme had been associated with a reduction in avoidable mortality.

These data were shared with participants in the AQ programme and presented at the regional QI meetings with local teams – providing previously unavailable analytics to a live and ongoing QI programme. The experimental mortality metrics were added to the team's site-level benchmarking reports in 2019 (see **Use Case 2**).





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Use Case 2 – Provision of benchmarking hospital reports for ARLD pathways (*"The first ninety days"*)

Click for explanation of dashboard		Summary Dashboard				Pooled data, 2014/15 to 2017/18		
(7)		2	3		5	6	7	
İİİ	737	269	395	666	627	430	763	а 8
Age	52.9	54.8	54.9	51.9	54.4	53.2	53.4	
Crude %	11.8%	13.0%	15.7%	12.3%	15.8%	12.6%	15.1%	
SMR ¹	83	90	114	95	109	101	109	
SMR ²	91	98	99	107	95	94	110	
LoS Median	7	7	7	7	7	6	6	
Crude %	42.5%	42.3%	49.2%	44.7%	42.2%	40.7%	41.2%	
SRR ¹	99	99	114	105	97	94	96	
SRR ²	100	98	114	104	97	94	96	
Crude %	24.5%	13.2%	12.9%	44.3%	20.8%	17.3%	15.1%	
Click for SMR ² funnel charts							≣€	$) \ominus$

The prototype analytics were presented as benchmarking reports (comparing hospitals) and shared with hospital teams, gathering feedback to refine the content and methods.

Focusing on seven hospitals and covering the period 2013/14 to 2018/19, the team generated site-level reports of activity, care process and outcomes and shared these reports with local clinicians.

A benchmarking dashboard was created to compare activity levels for index admissions for ARLD, tracking pathways from admission through discharge and 90-day events (readmissions, A&E attendances and outpatient visits).

Comparative performance for mortality, readmissions and rates of early post-discharge outpatient review were identified.

The pilot reports included geo-mapping at small area levels to illustrate not only admissions and burden, but patterns of pathway outcome according to place of residence.



In addition to providing site reports, the data were also integrated into regional clinical meetings with the AQuA ARLD Collaborative to inform the ongoing evaluation of the impact of the QI programme (as described in **Use Case 1**) and also to identify potential opportunities to further improve care pathways following hospitalisation (e.g. 2-3-fold variation was identified between hospitals in the proportion of patients attending an early hospital outpatient review following discharge from index admission).

Use Case 3 – Support for local services with bespoke analytics

Working with local clinical teams, the team also prepared bespoke data outputs to fill gaps in local analytics linked to work on avoidable mortality reduction for ARLD.

For example, one hospital team was undertaking retrospective case note reviews of all deaths from liver disease in response to an 'alert' on national metrics (outlier status on SHMI Liver disease sub-group for one fiscal year).

The team was able to provide granular data to confirm that there were case-mix differences from local trusts for that year.

Whilst the hospital was an outlier using simple case-mix adjustment, we showed there was no significant signal of excess mortality when adjustments were made for additional clinical severity flags in our risk-adjustment models.

Furthermore, the clinical team lacked any capability to determine whether there had been changes to the source (area of residence) of admissions with a fatal outcome, or if high-risk cases previously admitted to other local Trusts were being readmitted to their hospital during the year with a mortality alert.

Bespoke time-series maps were generated to provide the team with evidence to assist with their internal mortality review to understand the factors associated with mortality trends.

Use Case 4 – Deployment in a 'live' system to support the development of a prediction model for readmission in collaboration with Liverpool CCG and The Hartree Centre

To move beyond the interrogation of anonymized, linked administrative datasets hosted in the TRE, the team commenced work to further enhance the tools and prepare them for dissemination and deployment into live systems containing richer datasets to exploit opportunities for near-real-time analytics.



Working with the Innovation Agency, Liverpool CCG and The Hartree Centre, the Data Lab worked to transfer the algorithms for cohort identification and segmentation into the CCG's data warehouse containing hospital, primary care and other data.

The specific "use case" was to begin development of predictive models for readmission after index admission for ARLD, using both traditional regression models and exploratory statistical applications (e.g. random forest machine learning).

Working with the Hartree data scientist team, the project is exploring 'hypothesis-free' data mining to help identify factors associated with readmission and to create models using a richer, live dataset of relatively uncurated health and social care data.

This work will continue over the coming months with a view to establishing a proof-of-concept for a prediction model.

Use Case 5 – Evaluating the role of primary care contacts in the care pathway for ARLD

Recognising the need both to validate the regional work on external and larger-scale (national) datasets, and to extend the pathway analytics to include **primary care events**, the Data Lab developed a collaboration with a public health specialist (Dr Kate Fleming, Senior Lecturer) with experience and expertise in the use of CPRD for alcohol research.

The team obtained a download of national data from CPRD (linked primary care and 'HES') in order to test the locally-develop methods on national-scale data and further extend the methodologies to include data extracted from GP contacts.

During the final months of the project, the team will be developing codes lists and algorithms to further to validate and enhance the current techniques by adding primary care data items to the patient segmentation variables, candidate predictors and journey chronotypes.

This work will also build on the existing metrics to highlight primary care factors associated with inequality of outcome of index admissions for ARLD, specifically exploring opportunities for improving community-based intervention before first (index) emergency admission for ARLD.

CHALLENGES

Progress with work to extend the methodologies beyond hospital administrative data was delayed by a lack of access to linked primary care data from regional sources, despite efforts of partners in the programme to negotiate data access with controllers of primary care data.



Hence, plans were adapted and new projects pursued to (a) deploy methodologies into the Liverpool CCG dataset in collaboration with the Hartree Centre; and (b) obtain permission and undertake analysis of CPRD data hosted at the University of Liverpool.

Similarly, attempts to transfer the algorithms into local Trusts to deploy within internal business intelligence systems were delayed by Information Governance barriers and lack of hospital resources (time and expertise of internal BI staff). However, as part of the validation of the algorithm, the CHC team were able to generate a simple Excel-based tool to allow inhouse BI teams to process internally generated discharge coding extracts.

Work continues to establish ways to incorporate the cohort discovery algorithm into local live systems.





IMPACTS:

- The CHC work has generated novel analytical methods to identify cohorts of cases of ARLD from administrative datasets, characterise case mix and undertake granular segmentation and risk-adjustment, with new approaches to monitoring mortality and post-discharge outcomes. These methods have been shared with the local health economy and QI programme and have gained interest and traction with national programmes and leaders in the field. The work has been presented at national conferences (e.g. British Society of Gastroenterology, National Alcohol Conference) and shared in regional meetings with the clinical, public health and business intelligence communities.
- The CHC team's independent evaluation of the AQ programme using independent administrative data has generated evidence to show that a regional QI initiative focussed on improving specific care processes for ARLD can translate into reductions in avoidable mortality. This has not been reported elsewhere in the UK, and this work supports the current strategy for rolling out 'liver care bundles' nationally. The work has been submitted for publication and provided the foundation for submitting an NIHR Grant application.
- The team has established links with national leads at PHE, GIRFT, IQILs and Lancet Commission to develop plans for sharing methodologies and to collaborate on deploying CHC methods to national datasets in support of national scale QI initiatives for ARLD
- The CHC team is currently providing reports and knowledge transfer to **CHAMPS Public Health Collaborative** to support their plans for a Cheshire & Merseyside Acute Alcohol Services Dashboard.
- Clinical workforce development: During the project, two trainee doctors in the Academic Foundation Programme (AFP) undertook a four-month attachment working with the CHC team, gaining skills in data science and contributing their medical and domain knowledge to the pathway analytics development. One of the trainees won first prize in the annual ICAT AFP oral presentations for trainee doctors in the deanery for their work on CHC.



CONCLUSION/DISCUSSION:

The CHC Alcohol Pathway project has developed and tested a suite of new informatics tools to identify, characterise and track patient journeys from first unplanned admission through to post-discharge contacts with unplanned and elective services.

New composite metrics for comparing performance of providers were generated, incorporating risk-adjustment approaches that go beyond routine methods by focusing on a standardised starting point in the care pathway and leveraging greater segmentation and phenotyping of individual patients from the data.

These tools were integrated into a regional quality improvement programme for patients admitted as emergencies with ARLD, adding value by providing new capability to benchmark levels of potentially avoidable mortality.

This work enabled the local quality improvement community to track trends and generate intelligence to show measurable impacts of the programme on unexplained mortality and identify new targets for future QI interventions.

A prototype 'dashboard', incorporating the novel algorithms and pathway metrics was developed and shared with front line teams and the tools are now being shared within the local health economy, with leaders of national programmes and with international collaborators.

Ongoing locoregional projects with Liverpool CCG, The Hartree Centre and CHAMPS are seeking to further embed the methodologies into the evolving local LHS.



FUTURE PLANS/SUSTAINABILITY:

• Transfer of knowledge into local health economy

The methodologies have been shared locally with the Advancing Quality Alliance, Liverpool CCG and the Hartree Centre to augment local analytical capabilities and embed elements of the work into evolving local Learning Healthcare Systems. The code libraries, algorithms and metrics will be shared with the city's Civic Data Trust. Ongoing work with CHAMPS will further seek to incorporate CHC methods into the Cheshire & Merseyside Acute Alcohol Services Dashboard.

• Funding Application (NIHR Research Grant Application)

The CHC clinical leads have established a collaborative with academics in public health (Dr Kate Fleming; Prof Iain Buchan), biostatistics (Prof Paula Williamson) and psychology (Prof Bridget Young) at the University, members of the *Lancet Commission* and PHE (Prof Julia Verne, PHE) and national lead for the RCP's *Improving Quality of Liver Services* initiative (Dr James Ferguson, Birmingham) to submit a grant application to NIHR HSD&R. This work seeks to replicate and build on the CHC methodology to evaluate national roll-out of QI initiatives for ARLD pathways using national datasets (HES, ONS, CPRD and emerging loco-regional data assets with Liverpool CCG and/or Civic Data Trust).

• Collaboration with national programmes

Following the successful presentation of work at the National Alcohol Conference 2019 in December 2019, the clinical leads are in discussion with Public Health England (Professor Julia Verne) and the GIRFT lead for gastroenterology (Dr Bev Oates) to share methods and work collaboratively to add value to national initiatives by deploying elements of CHC methodology into these programmes.

• International collaboration

The CHC team, working with Dr Kate Fleming, have established links with a team of clinicians, public health experts and epidemiologists in Denmark, lead by Professor Peter Jepsen. Following a visit to Liverpool in December 2019, the CHC team is now collaborating to share algorithms and metrics with a view to deploying the methodologies on administrative datasets in Denmark.



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